Newborn Screening: Filling out the Form OKLAHOMA STATE DEPARTMENT OF HEALTH | CREATING A STATE OF HEALTH 1

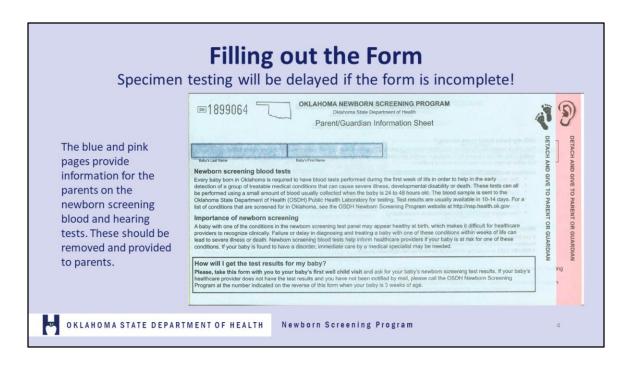
The Oklahoma State Department of Health Newborn Screening Program has updated the newborn screening filter paper kit. The purpose of this presentation is to review the new filter paper kit and discuss the information that needs to be collected with every specimen.

Filling out the Form Specimen testing will be delayed if the form is incomple	ete!
The filter paper kit number or serial number is a unique identifier for each filter paper. The filter paper kit number is a unique identifier for each filter paper. The filter paper kit number is a unique identifier for each filter paper.	DETACH AND GIVE TO PARENT OR GUARDIAN DETACH AND GIVE TO PARENT OR GUARDIAN CHART COPY DETACH AND PLACE IN MEDICAL RECORD
OKLAHOMA STATE DEPARTMENT OF HEALTH Newborn Screening Program	2

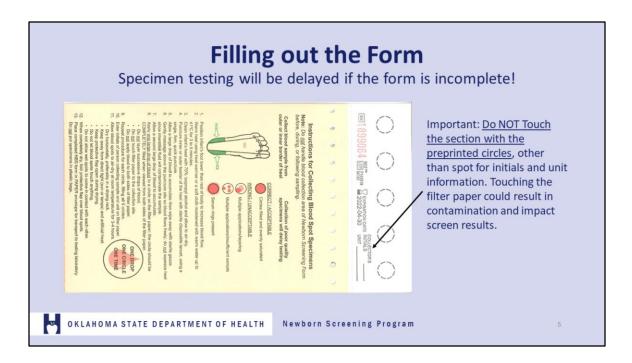
Before we review how to fill out the form, we are going to review each component of the filter paper kit. The top, white page, is the filter paper form or test requisition. Please note, the serial number is on the top left hand corner of the form. This is a unique identifier for each filter paper and is printed on each part of the filter paper kit.

Specimen testing will be delayed if the form is incomplete!				
The yellow copy belongs with the baby's medical record.	1889064			

The second page, the yellow page, is a copy of the form. The yellow page should be detached and placed in the baby's medical record



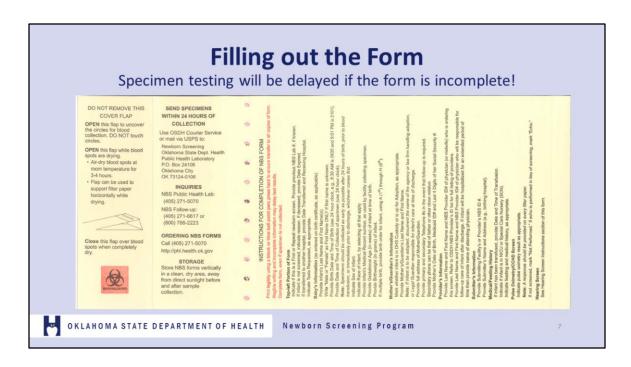
The third page, the blue page, provides information for the parents about the newborn screening test. The 4th page, the pink page, provides information for the parents about the newborn hearing screening. The blue and the pink pages should be removed and provided to the parents prior to discharge.



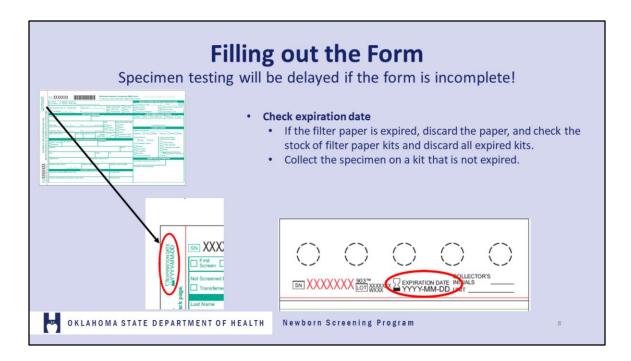
The 5th page has two parts, the white part with the 5 circles, is the filter paper where the specimen is collected. It is important to not touch the filter paper as this could contaminate the specimen and impact the screen results. The manila portion provides the instructions for collecting the specimen.

Filling out the Form Specimen testing will be delayed if the form is incomplete!
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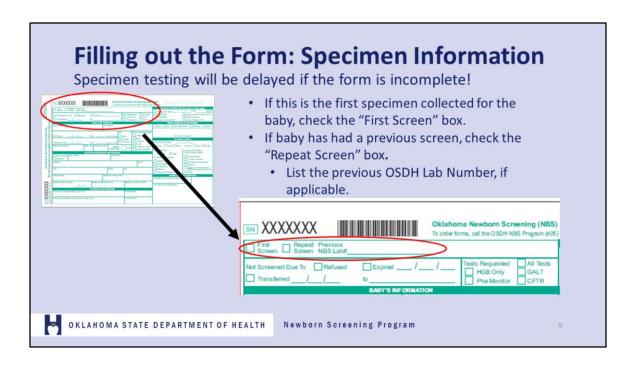
The front of the last page of the filter paper kit, provides instructions on how to complete the hearing screen portion of the newborn screen form.



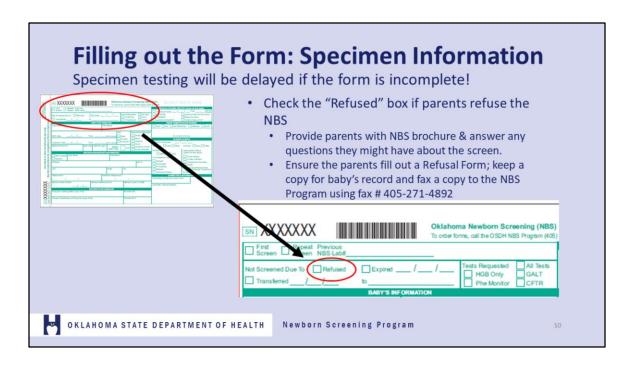
The back of the filter paper kit also provides instructions on how to complete the remainder of the form, where to send specimens, how to order forms, and how to store the unused filter paper kits. Finally, the flap is used to support the filter paper while drying and then cover the blood spots once dry to help protect them during transport.



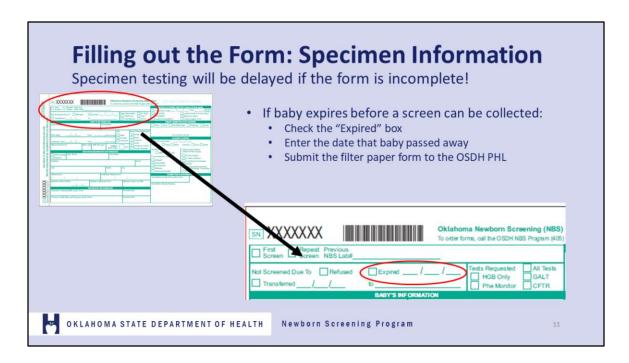
Check the expiration date before filling out the form or collecting the specimen. There are two places that the expiration date can be checked. The first is on the front of the kit on the top left hand corner. The second place is on the filter paper portion below the 5 pre-printed circles. If the filter paper has expired, discard the kit, check your stock of filter paper kits to ensure that ALL of the expired kits are discarded. Collect the specimen on a kit that is not expired. Testing will not be completed on specimens that are collected on an expired kit, delaying screening for the baby. Now we will move on to explain how to correctly complete the filter paper form.



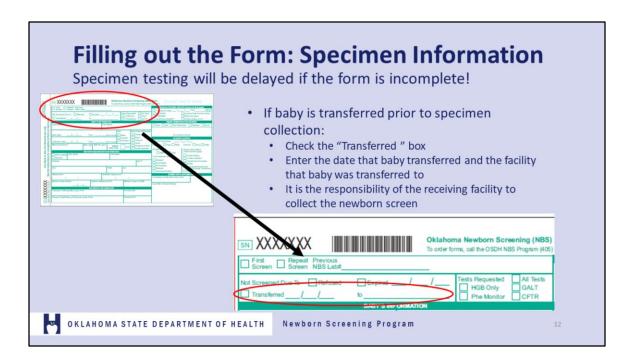
Please note that specimen testing will be delayed if the form is not filled out completely. This PowerPoint will cover each section of the form and review the requested information. The first section on the form is specimen information. If this is baby's initial screen, meaning no screens have previously been collected, check the first screen box. If baby has had a previous screen collected check the repeat screen box and enter the previous OSDH newborn screening lab number if known. You can also enter the filter paper serial number in this section, if the lab number is not available.



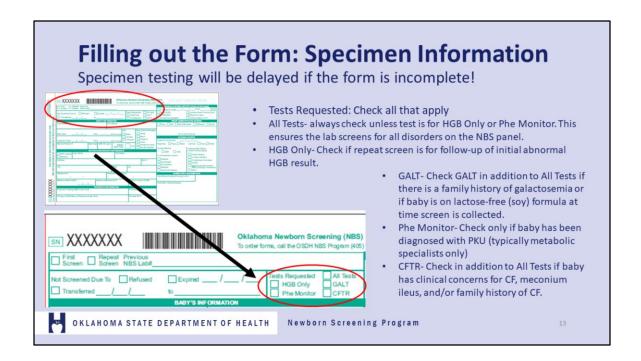
If the baby is not screened due to refusal, please check the refused box and complete all demographic information. Provide parents with the newborn screening brochure and answer any questions they may have. Ensure that parents fill out the refusal form, the refusal form can be found on the Newborn Screening website. Keep a copy of the refusal form for the baby's medical record and fax a copy to the NBS Program at fax # 405-271-4892.



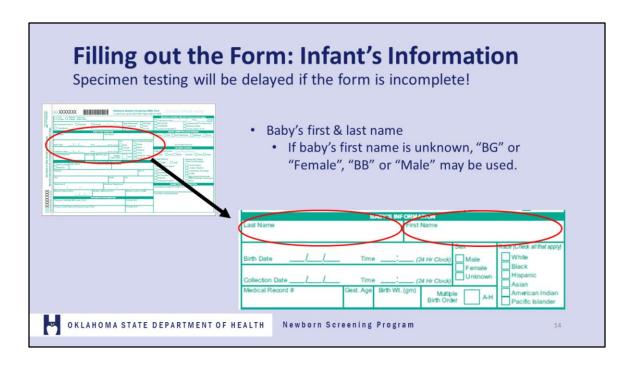
If the baby is not screened because he/she expired before the specimen could be collected, check the expired box and enter the date baby passed away. Complete the section for mom and baby's demographic information and send the completed form to the NBS PHL.



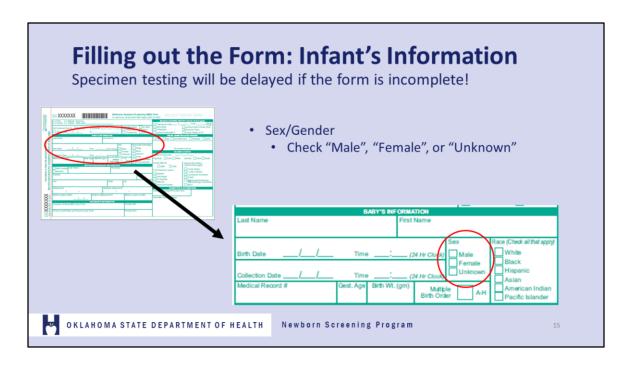
If the baby is transferred to another facility before the screen can be collected, check the transferred box, and enter the date baby was transferred and the facility the baby was transferred to. Complete mom and baby's demographic information and send the completed form to the NBS PHL.



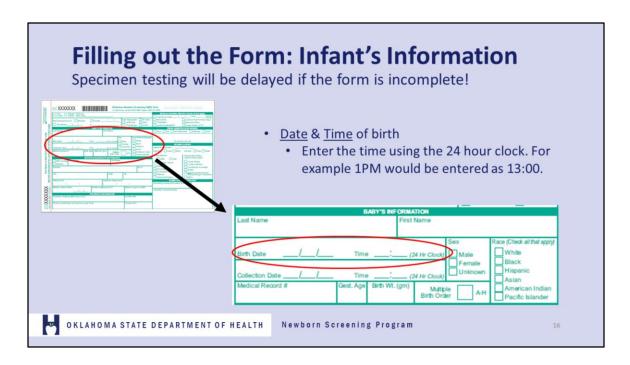
In the tests requested section, all tests should always be checked, unless the test is for a hemoglobin only screen or a phe monitor. Hemoglobin only screens are done when the initial screen is out of range for a hemoglobin trait. At about 4 months of age, the NBS program will request a hemoglobin only screen to confirm baby's trait status. Phe monitors are only collected for baby's who have been diagnosed with PKU and are typically only collected by a metabolic specialty clinic. GALT should be checked, along with ALL Tests, if there is a family history of galactosemia or if baby is on lactose free or soy formula at the time of collection. CFTR should be checked, along with ALL Tests, if there are clinical concerns for cystic fibrosis, baby has a meconium ileus, and/or there is a family history of cystic fibrosis.



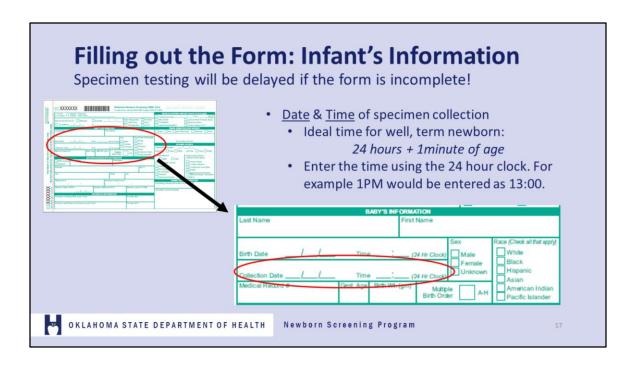
This section will cover the baby's demographic information. Include first and last name. If possible, please use the baby's name that is entered on the birth certificate. If baby's first name is unknown you may enter the sex of the baby, such as BG or female for girls and BB or male for boys.



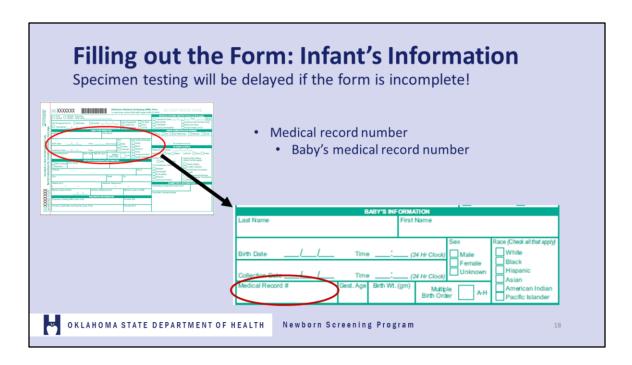
Enter the sex of the baby- male, female, or unknown if you are not able to accurately identify the sex of the baby



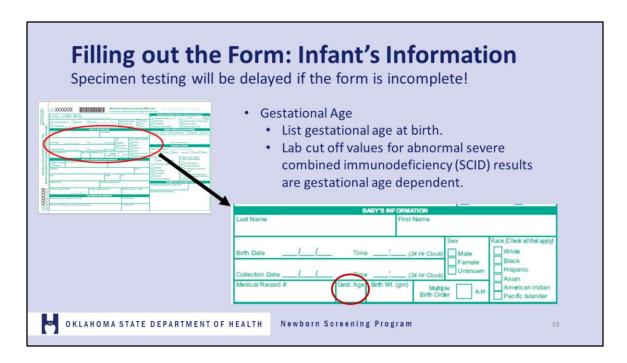
Enter the date and time of the baby's birth. When entering the time use the 24 hour clock or military time. For example 1pm would be entered as 1300.



Next enter the date and time the specimen is collected. Ideally for healthy full term newborns the screen will be collected at 24 hours plus 1 minute of age. Please ensure when the time of collection is entered the 24 hour clock or military time is utilized. For example 1pm would be entered as 1300.



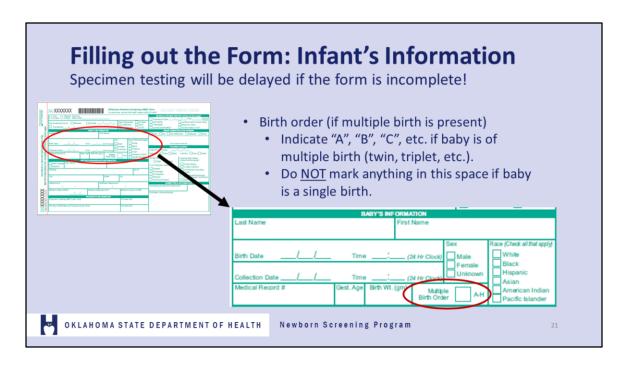
Please enter baby's medical record number in this box. This number may need to be used if baby has an abnormal screen and the nbs follow up team needs to call the hospital for additional information.



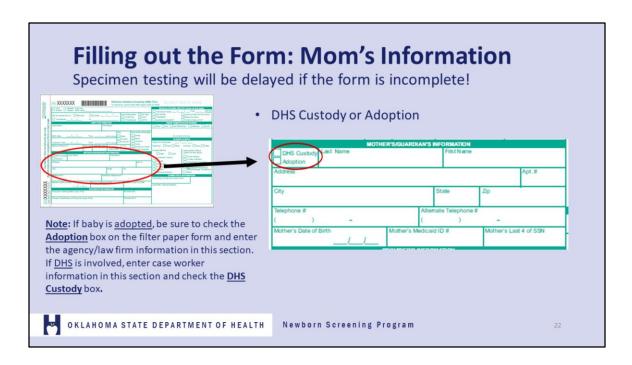
List the baby's gestational age at birth. This is important because lab cut offs for abnormal severe combined immunodeficiency (SCID) results are gestational age dependent.

	Form: Infant's Information be delayed if the form is incomplete!		
	 Birthweight (in grams) Lab cut off values for abnormal congenital adrenal hyperplasia (CAH) results are dependent on birth weight. 		
	BABY'S INFORMATION Last Name First Name		
	Sex Race (Check all that apply) Sex Race (Check all that apply) White White Sex Sex Race (Check all that apply) White Sex Sex		
OKLAHOMA STATE DEPARTMENT OF HEALTH Newborn Screening Program 20			

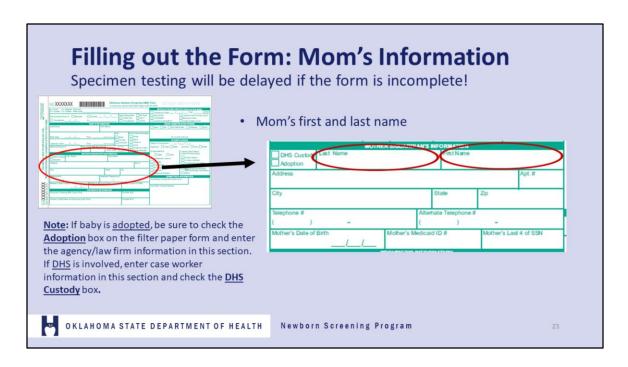
Slide 20: Enter the baby's birth weight in grams. Lab cut offs for abnormal congenital adrenal hyperplasia (CAH) results are dependent on baby's birth weight.



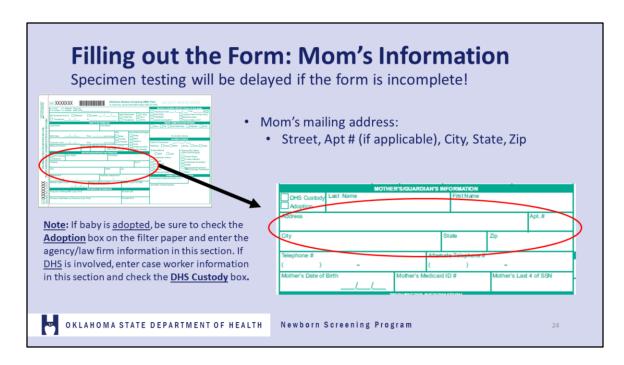
If baby is of a multiple birth, such as a twin or a triplet, enter the baby's birth order. For example if baby is the first twin born, enter an A here. If baby is a single birth this space should be left blank.



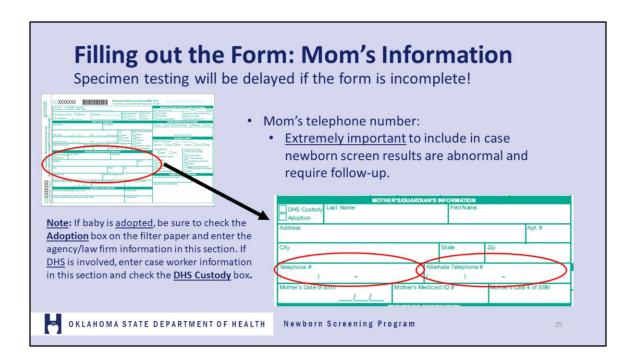
The next section of the form is mom's or guardians demographic information. Please note that if baby is adopted, you will check the box for adoption and then enter the adoption agency or law firm information in this section. If baby is in DHS Custody, mark the DHS custody box and enter the DHS case worker information in this section.



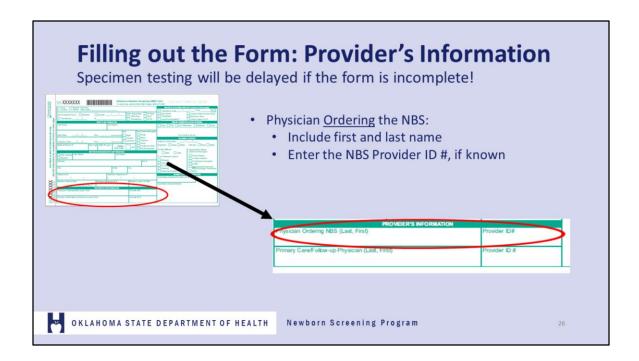
If adoption and/or DHS custody do not apply, please complete this section with birth mom's demographic information including mom's first and last name.



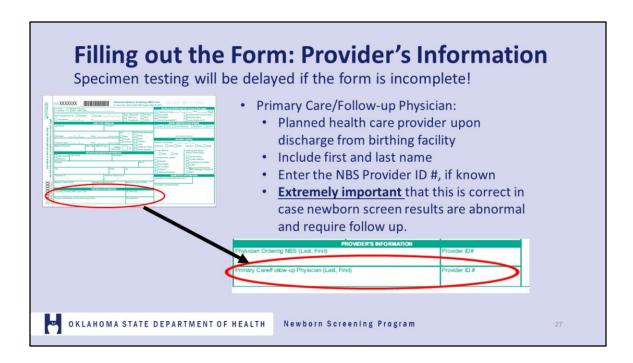
Enter mom's mailing address including full street address with apartment number, if applicable, city, state, and zip code. This is very important if parents need to be contacted for follow up of abnormal screen results.



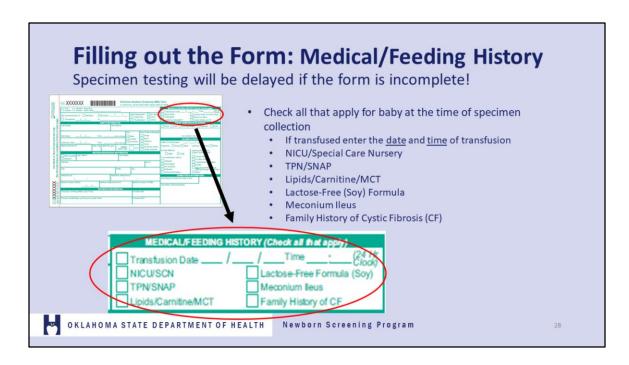
An accurate telephone number for mom is also very important if mom needs to be contacted for follow up related to abnormal screen results. There is also now a spot for an alternative phone number, if one is available.



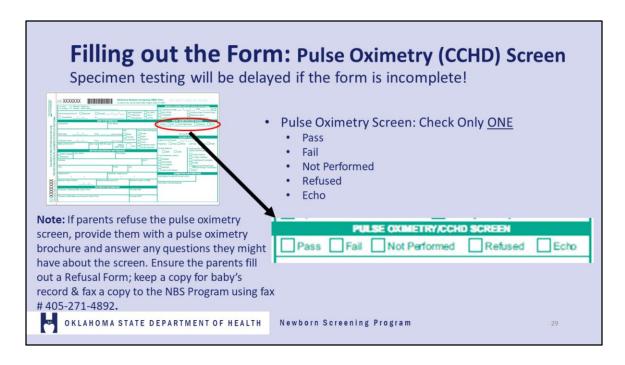
You will notice on the new form, we are requesting the information for the physician ordering the newborn screen in the hospital. This includes, last name, first name, and newborn screen provider ID.



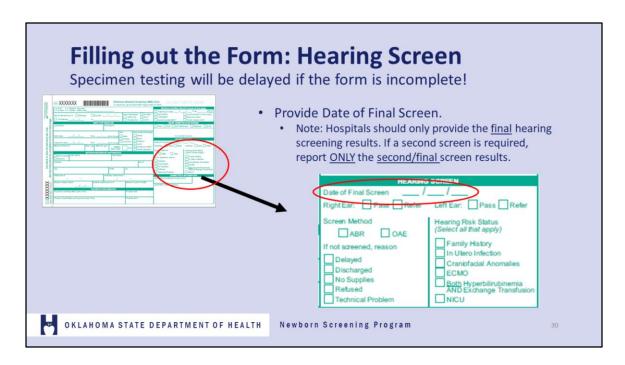
We are also requesting the information for the follow up or primary care provider. This is the provider that will be seeing the baby outside of the birthing facility. Please include last name, first name, and provider ID. If the nbs provider ID is not known, please enter the phone number for the provider. It is extremely important that this information is correct in case the newborn screen results are abnormal and follow up is required. The NBS program will contact the follow up PCP to initiate follow up activities.



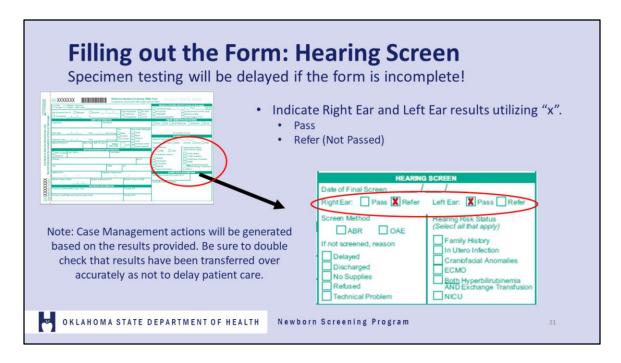
The top right section of the form is for baby's medical/feeding history. All of these variables can impact the screen results and/or follow up. Please check all that apply for the baby at the time of specimen collection. If baby has been transfused, please enter the date and time of the transfusion using the 24 hour clock or military time.



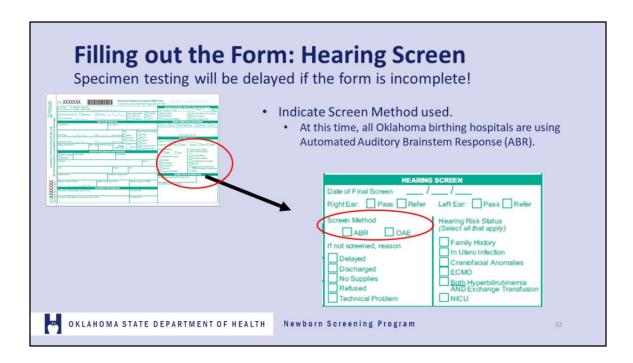
For pulse oximetry or CCHD screening results, only one box should be checked-choose either pass, fail, not performed, refused, or echo. If parents refuse the pulse oximetry screen, please provide them with the pulse oximetry brochure and answer any questions they might have. The parents must sign the refusal form. A copy of the refusal form should be kept for the baby's medical record and a copy should be faxed to the NBS program at 405-271-4892.



When filling out the Hearing Screening section, provide the Date of the Final Screen. For most babies, they will pass the initial screening. However, if a second screen is required, report <u>ONLY</u> the <u>second/final</u> screen results.

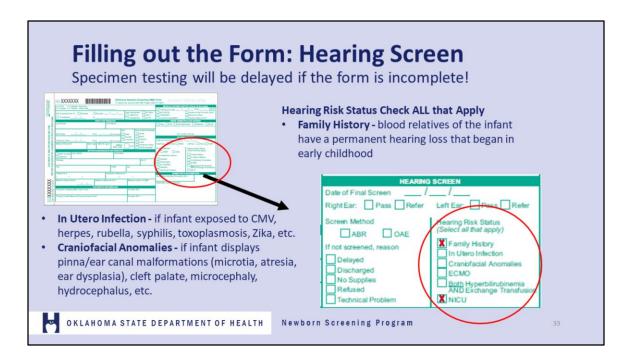


After completing the hearing screening, the equipment will indicate Pass or Refer for each individual ear. Document Right Ear and Left Ear results utilizing an "x." Make sure you enter the correct results for the each ear and ensure only one result is selected per ear, as a child can NOT both pass and refer a screening. NEVER combine the results of the first and second screening on the form. Combining results could miss a Unilateral, single sided, hearing loss which could greatly impact a child's life outcomes.



Be sure to indicate the screen method on the filter paper. Currently all Oklahoma hospitals utilize Automated Auditory Brainstem Response – also known as ABR.

Since some children will have a delayed screening, such as those in the NICU, do <u>not</u> prefill screen method. Only mark the method if a screening HAS being completed.

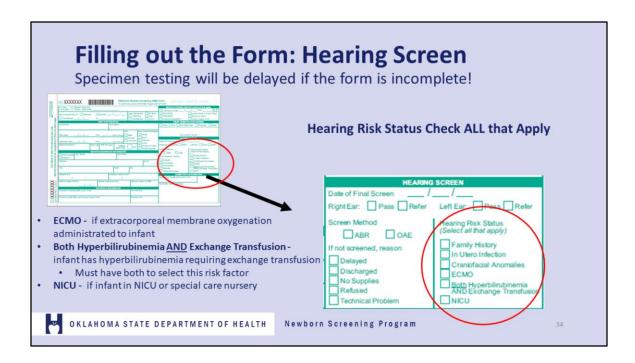


Completing the ABR is only the first half of the screening. Risk factor screening must be completed as well. Make sure you select ALL risk factors that apply. This may require reviewing the patient's chart or asking about family history. Remember that family history includes a blood relatives of the infant have a permanent hearing loss that began in early childhood. This does not include family members who lost their hearing due to age or circumstances such as loud noise.

If a child has an in utero infection, make sure to mark the form appropriately. A list of possible infections is listed in the instruction section.

Craniofacial anomalies can be an indicator of unseen internal structural issues that could impact hearing. Be sure to complete a visual inspection prior to the screening to see if malformations are noted.

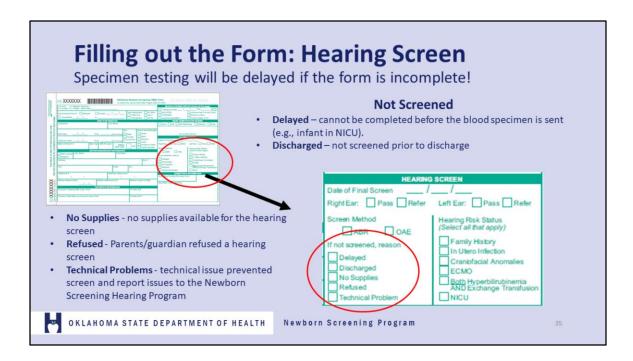
Complete this section even if hearing screening is delayed.



Mark ECMO if this applies to the child. Research has shown that ECMO is linked with delayed onset hearing.

Both **Hyperbilirubinemia AND Exchange Transfusion** must be present to select this option as risk factor on the new form.

Finally, select the NICU box if a child has been in the NICU or special care nursery.



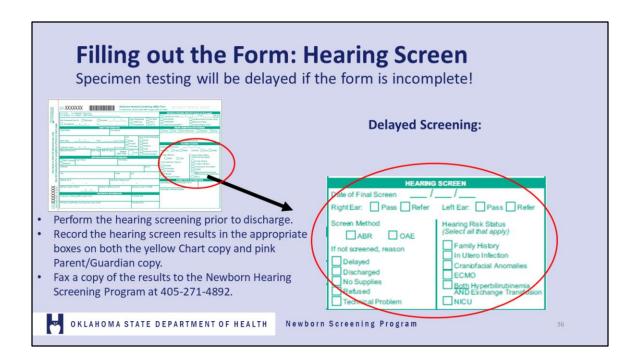
If hearing screen cannot be performed, indicate the reason by selecting the appropriate box in the "If not screened, reason(s)" section.

If the hearing screen is delayed, mark delayed. Do not delay sending the blood specimen to the public health lab.

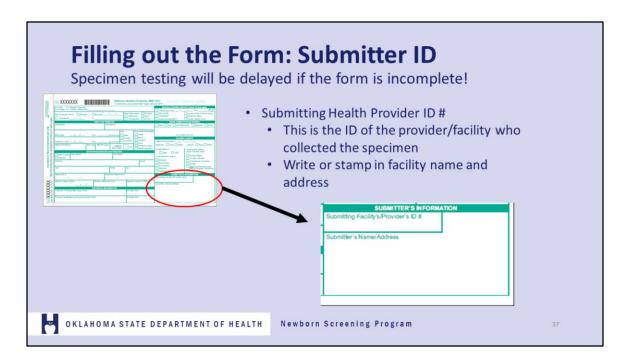
If baby was discharged prior to performing the hearing screen, mark discharged and send the blood specimen to the public health lab. The parent/guardian will need to be contacted to bring the baby back for a hearing screen.

If baby was not screened due to no supplies, mark no supplies and send the blood spot specimen to the public health lab. The parent/guardian will need to be contacted to bring the baby back for a hearing screen when supplies are received. If the baby was not screened due to refusal, please check the refused box and complete all demographic information. Provide parents with the newborn screening hearing brochure and answer any questions they may have. Ensure that parents fill out the refusal form, the refusal form can be found on the Newborn Screening Website. Keep a copy of the refusal form for the baby's medical record and fax a copy to the NBS Program at fax # 405-271-4892.

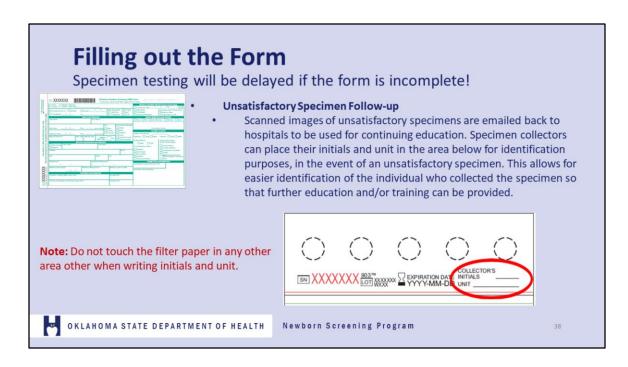
If the baby was not screened due to technical problems, report the issues to the Newborn Screening Hearing Program so that actions can be taken to ensure all babies receive a screening in compliance with state mandates.



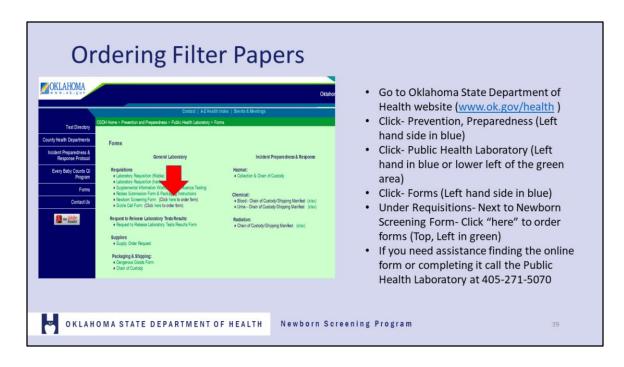
If a screening was delayed, perform the hearing screening prior to discharge. Record the hearing screen results in the appropriate boxes on both the yellow Chart copy and pink Parent/Guardian copy. Fax a copy of the results to the Newborn Hearing Screening Program at 405-271-4892. Please be certain that the infant's name and NBS Form Serial Number are legible on the photocopy.



The lower right hand corner of the form is where the submitter ID is entered. This is the newborn screening ID number of the provider or facility who collected the specimen.



When unsatisfactory specimens are received the nbs phl emails scanned images of the unsatisfactory specimen to hospitals to use for continuing education. The individual collecting the specimen can place his or her initials in the lower right hand corner of the filter paper, under the 5 circles where the blood is collected. This allows for easier identification of the individual who collected the specimen for further education and or training. Do not touch the filter paper anywhere except where the initials and unit will be written.



You can order filter papers online by going to the Oklahoma State Department of Health website, www.ok.gov/health. Then you will click Prevention and Preparedness on the blue left hand navigation pane. Once on the next screen click the Public Health Laboratory, this is on the blue left hand navigation pane or on the lower left of the green portion of the screen. Then you will click on Forms in the blue left hand navigation pane. That should bring you to a screen that looks like this. On this screen, under requisitions next the Newborn Screening Form click here in green. This will open an online form that you can complete and submit to order filter papers. If you have trouble locating the form or completing the form please call the NBS PHL at 405-271-5070.

Tips/Reminders

- Specimen testing will be delayed if the form is not completely filled out
- Inaccurate/incomplete information can delay follow up
- One large drop of blood should be placed in each circle, not multiple drops.
- · Do not place stickers on the form



Newborn Screening Program

As the presentation concludes, we wanted to provide you with a few last minute tips and reminders. Remember specimen testing will be delayed if the form is not completely filled out. Inaccurate/incomplete information can delay follow up for a baby that has abnormal screen results. One large drop of blood should be placed in each circle, not multiple drops. Do not place stickers on the form, if your facility requires a sticker be placed on the form, place it on the back of the white demographics page.

Oklahoma State Department of Health Newborn Screening Program

NBS Follow Up

Phone: 1-405-271-6617 option 2 Toll Free: 1-800-766-2223 option 2

Fax: 1-405-271-4892

NewbornScreen@health.ok.gov

NBS Public Health Lab

Phone: 1-405-271-5070



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Thank you for taking the time to watch this video. The Newborn Screening Program appreciates your assistance in ensuring every baby in the state of Oklahoma receives a newborn screen. If you have questions please use the information on the slide to contact us.